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ABSTRACT

The booklet, one of a series of guides developed by Project STEPS (Steps Toward Effective Production of Speech), presents information for parents and deaf-blind children. Total deafness and blindness and the problems of deafness and blindness are considered, as are the nature of deaf-blindness and its special problems (e.g., eating problems, mannerisms or self stimulating behaviors). Parents are offered suggestions for obtaining medical services, talking to the child, establishing routines, and taking time for themselves. Descriptions of resource people (including social workers and otologists) and groups (such as vocational rehabilitation and service clubs) are given. The booklet concludes with brief portraits of four individuals who are deaf-blind. (CL)

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Steps Toward Effective Production of Speech (STEPS) A Set of Booklets for Parents of Deaf-Blind Children

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Department of
Communicative Disorders
Area of Special Education
Partlow State School and Hospital
1983

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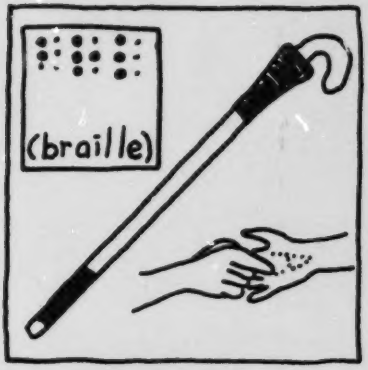

TOTAL DEAFNESS AND BLINDNESS

Total deafness and blindness are rare. Almost everyone who is deaf has some hearing left. The same is true of sight. Almost every blind person has some sight left.

Only a few people have no hearing and no sight at all. They will not get help from a hearing aid and glasses. Even so, they can learn many, many things. They

will learn by touching and other ways.

At first a deaf baby may not seem to hear anything. Later his parents may notice that he only hears very loud sounds. For example, he may turn to the sound of a car horn if it is close. This is a good sign because it means he has some hearing.

A deaf baby must be trained how to use his hearing. After a while he may notice more and more sounds.

A blind baby may not seem to see anything. Later, you may find that he turns to a bright light. Or he may move his hand between his eyes and the light. These are good signs because it means he has some sight left. His sight needs to be trained so he can make the best use of it.

Almost every deaf-blind child can hear and see something. He may only hear very loud sounds and see very bright lights. With training he can learn how to use his hearing and sight. Hearing aids and glasses may also help him.

PROBLEMS OF DEAFNESS

Children learn to talk because they can hear speech. They hear their parents and others talk and they hear their own speech.

When a child is deaf, he does not hear speech. Or what he hears is not clear. This is why he does not learn to talk like other children.

A deaf baby begins to use his voice like other babies. When he is about six months old, he says things like *"buh-buh"* and *"la-la."* He squeals and grunts and makes sounds with his voice.

When a deaf baby is a year old, he does not start to talk. He does not say words like babies who can hear. He may say *"mama"* but nothing else. This is because he can not hear what people say to him. By his first birthday he is using his voice less and less. This is because he does not hear his own voice.

He will not understand speech well. Hearing aids may help him. He needs to use his eyes, as well as his ears, to understand what people say.

Deaf children need many kinds of special help. They need:

- ☐ Hearing aids and training in how to use them
- ☐ Training in lipreading
- ☐ Training in speech and language
- ☐ Special teachers at school

Not all children who are deaf will learn to speak clearly. Some will learn to talk by making signs with their hands.

PROBLEMS OF BLINDNESS

A baby crawls and walks around because he sees things he wants. He sees a toy across the room and crawls over to get it.

A baby who is blind may only see bright light. He does not know what is across the room. He may not even know what is right beside him.

A blind baby may be afraid to move around. He may cling to a person he knows. You can help him learn not to be afraid. You

can move around the room with him.

Later, a blind person can learn to get around. He may depend on what he hears and what vision he has left. He may also use a cane or a guide.

A baby who can see will learn to know his mother's face. He knows her even if she is across the room. A blind baby may not know his mother's face. It may be a blur no matter how close she is. A blind child learns to tell who a person is by the sound of his voice.

A blind child may not learn to read as easily as a child who can see. This is one reason for special teachers. Glasses, special TVs, and other vision aids may also help in learning to read.

Blind children need many kinds of special help. They need:

- ☐ Vision aids and training in how to use them
- ☐ Special help in reading
- ☐ Training in getting around alone
- ☐ Special teachers at school

Some blind children will never learn to read print. They will learn to read Braille instead.

PROBLEMS OF DEAF-BLINDNESS

A deaf-blind baby faces many problems. He will not learn to talk and listen like children who can hear. Also, he will not learn to read and write like children who can see. A deaf-blind baby does not learn to walk around alone as soon as other children.

Because he does not hear and see like other babies, he needs special help. There are many ways

to help a deaf-blind child learn.

- ☐ A child's family can help at home.
- ☐ Teachers and counselors can help at school and other places.
- ☐ Hearing aids, glasses, and other aids can help.

A child who is deaf and blind needs special teachers. At first a teacher may visit the baby's home. The teacher can answer some of the parents' questions about deaf-blindness. The teacher will also tell and show the parents things to do for the baby.

When the deaf-blind child is older, he will need special teachers at school. He will need more help from teachers than other children. Later on he will need special help in learning a job.

Many people have special training so they can help deaf-blind children. Some of these people are listed on pages 33 to 37. There is much that can be done to teach a person who is deaf and blind.

There are many groups that can help people who are deaf-blind. Some of them are listed on pages 37 to 45.

SOME OTHER PROBLEMS

☐ A deaf-blind child may do things later than other children. He may crawl and walk later. He may feed himself and be toilet trained later. This is to be expected because of his poor hearing and vision. It takes time and patience to teach him.

☐ Some deaf-blind children do not like to be touched. When a child does not know someone is near, a touch may frighten him. It

may help to give a warning that you are near. For example, tap on your child's chair and then gently touch his arm.

If your baby does not like to be cuddled, try holding him at pleasant times. For example, hold him when you first give him a toy he likes. Or, cuddle him when you are drying him after his bath.

☐ Many deaf-blind children have some kind of eating problem. They may not like chewy foods because they are not used to them. They may not like the way some food feels, or tastes, or smells. Or they may have trouble chewing and swallowing.

There are many ways to teach a child to eat new foods. For example, mix a new food with something he already likes. Any

change in food should be made a little bit at a time.

☐ Almost everyone has some mannerisms or self-stimulating behaviors. A mannerism is swinging your leg, drumming your fingers, or jingling coins in your pocket. Deaf-blind children also have mannerisms. Their mannerisms may be poking their eyes or rocking back and forth. Or they may wave their fingers between their eyes and the light.

Mannerisms may annoy other people; they may even hinder learning. A mannerism, such as a child's hitting his head, may harm him. He can learn to do these things less often, or not at all.

☐ STEPS booklet 6 gives some ways to help with these problems.

WHAT TO DO FIRST

Take your child to the doctor if you think he has a hearing or vision loss. The doctor can tell you whether he needs treatment. The doctor will probably refer you to another doctor who treats ear or eye problems.

Sometimes the doctors can not improve a child's hearing and vision. If hearing and vision can not be improved, hearing aids and glasses may help. An audiologist

can tell you if your child should wear hearing aids. He can also tell you what kind of aids to get.

An ophthalmologist (medical doctor) or an optometrist can tell you whether your child needs glasses. This should not be put off until a child is older. Babies who are only a few months old can use hearing aids and glasses.

Many parents can not pay for a doctor's care, a hearing aid, or glasses. If you can not pay for these things, ask for help. Ask your local office for crippled children's services. Or ask your minister, priest, or rabbi how to get help. Some agencies and clubs help to buy things for deaf-blind children. Some of these groups are listed on pages 37 to 45.

Next, a deaf-blind child needs to be taught how to use his hearing aids and glasses. Get in touch with your local school. Find out how to get a teacher of the deaf-blind to visit your home.

A teacher of the deaf-blind can help you train your child at home. The teacher can also tell you when your child is ready for school.

GET CLOSE TO YOUR CHILD

There are many times during the day when you can get close to your child. For example, when

you are helping him to bathe, or dress, or eat. These are good times to talk to him and get to know him.

Another way to be close to your child is to move him near you. Move him to where the action is. If you are washing dishes, put your child in his high chair near you.

Try moving your child's playpen near you while you are working. This way he will begin to learn what is going on around him. Another time to bring him close is when you are watching TV.

TALK TO YOUR CHILD

Talk to your child when you are near him. This is the way he will learn what speech is. He will also learn why we talk to each other.

Let your child know when you are going to talk to him. You could say his name first. Or you could touch him and turn him to face you.

Try putting your child's hand on your cheek or neck when you

talk. This will let him feel that something is happening. After a while he will lea that people talk to each other.

When you are feeding him, talk about his food. You could say, *"Bobby, try the green spinach. That's a good bite! Maybe you like apples better. They're sweet and smell nice."*

Talking to your child should help him to talk. If he has a hearing aid, talk close to its mike. (See STEPS booklet 1.) If he does not have an aid or if he is not wearing his aid, talk in his ear. Do not shout. Talk in a normal voice or a little louder. Talk about one inch from his ear.

Say the same things to a deaf-blind child you would say to any child.

- ☐ Talk simply.
- ☐ Talk about what he is doing.
- ☐ Talk about what you are doing.
- ☐ Talk about things that are near.
- ☐ Say the same thing again and again.

When he makes sounds, show him you are happy. Give him a pat or a hug. He may tell you things by his sounds. When he does, show him you understand. If his sound tells you he is hungry, give him something to eat. This will make sounds mean something to him.

Sometimes when you are together, your child will make sounds with his voice. When he does, you should make the same sounds. Later on, he may try to

make the sounds you make. This is how he will begin to learn the names of things.

His first tries at names may not even sound like words. Show him you are pleased when he tries to make the sounds you make.

There is another way to teach him names. Show him an object and say its name. Give him a ball and say, *"Ball."* Sometimes put his hand on your face when you say, *"Ball."* Then he can tell how the sound feels.

Suppose you are ready to give him a bath. Say, *"Bath,"* with his hand on your face. Then put his hand in the water. Then say, *"Bath,"* again before putting him in his tub. If he tries to say, *"Bath,"* show him you are pleased.

The drawing on page 20 shows one way to talk to a baby. She

does not have her hearing aids on. This is why her mother is talking into her ear.

FOLLOW A SCHEDULE

Have a regular time to do things with your child. This will make him feel more secure. And it will make life easier for the rest of the family.

Get your child up about the same time every day. Help him bathe and dress about the same time each day. Have his meals at a regular time. Put him to bed

about the same time every night. Try not to let him sleep a lot during the day. Then he will be more likely to sleep all night.

If your child has hearing aids and glasses, put them on him every day. If he is just starting to use them, put them on for a short time. You might put them on him after breakfast while you are with him. Then put them on again in the afternoon after his nap.

At first your child should wear his hearing aids and glasses a little bit at a time. After a couple of weeks, he should wear them longer and longer. Most children should wear their hearing aids and glasses all day. Put them on when dressing. Let your child know they are needed as much as clothes.

If you do not know how much your child should wear his hearing aids, ask the audiologist. If you do not know how much he should wear glasses, ask the optometrist.

Each day set aside some time to spend with your child. Begin a little bit at a time. When you are with him, show him things. Let him feel them and hold them. Move around the room with him. Let him find where things are. Play with him as you would with other children. And do not forget to talk to him.

Sometimes things happen that make you change your schedule. This happens to everyone. Get back to your schedule as soon as you can.

GET REGULAR CHECKUPS

Your child needs regular checkups and tests just like other children. He will need to see his doctor for booster shots. And he should see his dentist for dental care. The deaf-blind child also needs to see other specialists. He should see his ear doctor and eye doctor once a year.

Your child may need some tests every year also. These may be tests of hearing and vision. They tell if your child's hearing and vi-

sion have changed. They also tell if his hearing aids and glasses need to be changed. Your child needs these checkups. They will let him make the best use of his hearing and vision.

Some tests tell what to expect of your child. These are called intelligence tests. They can help in planning for his training and teaching. Other tests tell how well he is learning. These are called achievement tests. They may show progress that parents and teachers may not have noticed.

It is hard to make sure your child gets all the checkups he needs. Make a note on your calendar of each date for a checkup. Plan ahead so you will be able to get there. Try to be on time. If something keeps you from getting there, call to let them know.

Sometimes a problem may come up between checkups. If it does, call the specialist. Let him know what the problem is. Then he can tell you what to do.

TAKE TIME FOR YOURSELF

Parents must take some time for themselves. You need times away from your deaf-blind child.

- ☐ Times when you can be alone.
- ☐ Times when you can get out of the house.

- ☐ Times with just your husband or wife.
- ☐ Times when you can do things with other family members and friends.

You can not be the only person in your deaf-blind child's life. A deaf-blind child needs to be with other people. He also needs to learn to get along with other people.

A parent needs time to do things around the house. Plan to do these things during your child's nap time. Another time for these things is when your child is at school.

A parent needs to go out to shop and do errands. Plan to do these things at regular times. Ask someone to stay with your child at these times. You can ask a

neighbor, a relative, or a teenager who knows your child.

Sometimes a family may want to do something together that would not be fun for a deaf-blind child. Plan ahead for something like this. Get a neighbor or a sitter to stay with your deaf-blind child.

REMEMBER—

① GET CLOSE TO YOUR CHILD.

See page 18.

② TALK TO YOUR CHILD.

See page 20.

③ FOLLOW A SCHEDULE.

See page 24.

④ GET REGULAR CHECKUPS.

See page 27.

⑤ TAKE TIME FOR YOURSELF.

See page 29.

PEOPLE WHO CAN HELP

Many people can help your deaf-blind child. Doctors are among those who can help. You may need to look around for one you like.

You will want to find a doctor who gets along well with your child. Also, he should know about the kind of problems deaf-blind children have. He should know about rubella syndrome, Usher's syndrome and other problems.

Do not be afraid to talk to the doctor about your child's problems. Parents are often the ones to see a problem first. This is because they are with their child every day. Ask the doctor questions when you need to know more about your child's problems.

Your child's ears and hearing should be checked regularly. He should see an **otologist**. This is a medical doctor who treats ear problems. Your child should also see an **audiologist**. This is the person who tests his hearing and hearing aids.

The doctors who check your child's eyes and sight are the **ophthalmologist** and the **optometrist**. The ophthalmologist is a medical doctor who treats eye

problems and fits glasses. The optometrist tests vision, fits glasses, advises special exercise, and refers for medical care.

A **psychologist** can also help the deaf-blind child and his family. He gives two kinds of tests. One kind tells how well a person is able to learn. It also tells if he has learning problems. The other kind tells how a child is growing socially and emotionally.

Some psychologists see a lot of children with handicaps like deafness and blindness. Try to find one of these for your child.

A psychologist can help the family of a deaf-blind child, too. He can help by advising or counseling them. For example, it is normal to feel "down" or depressed sometimes. But if you feel depressed most of the time, a

psychologist may be able to help. He might help you work out a schedule. This could help you do all the things you must do, and make you feel better.

A **teacher of deaf-blind** knows about the special problems of deaf-blind children. If your child is still a baby, the teacher will work with you. He will tell and show you what to do at home. He will teach you how to help your child learn. The teacher can also help you get your child used to hearing aids and glasses.

After your child starts to go to school, talk to his teacher regularly. The teacher can still tell you how to help at home.

Some agencies or groups have a **social worker**. This person can refer you to other people or groups who can help. He may also arrange times for you to visit them.

A child may have another problem beside deafness and blindness. If he does, he may need to see other specialists. If he has cerebral palsy, the doctor may send him to a **physical therapist** or **occupational therapist**.

GROUPS THAT CAN HELP

Many groups or agencies help people who are deaf-blind and their families. Some of them can

answer your questions. Others may refer you to groups near you that can help. Some of them buy hearing aids and vision aids for children. Or they may pay part of the costs.

Crippled children's services help some families pay for things a deaf-blind child needs. They may provide tests, medical care, and aids. Their rules vary from one state to another. Call your local office if you need their help. It should be listed in the telephone book under the name of your state.

Departments of public assistance may also pay for things a deaf-blind child needs. You can call your local office to find out what they can do. The name of this department is not the same in all states.

Vocational rehabilitation services may provide tests, medical care, aids, and training. They also help find jobs for deaf and blind persons. They help people who are 16 years and older. Sometimes they help children as young as 14 years. Look for your local office under the state listing in the telephone book.

The **Social Security Administration** may help support children and adults. To find out about the Supplemental Security Income, call your local office. Look it up under U.S. Government in the telephone book.

Medicaid may help if you have a limited income or large medical bills.

Service clubs will sometimes buy aids for children. They may also pay for surgery. Lions Clubs

have a special interest in children with vision loss. There are other service clubs that may help too. You might call your local American Legion Post, Elks Lodge, or Masonic Lodge. Or check with the Jaycees, Pilot Club, Civitan Club, Shrine Club, Rotary Club, Sertoma Club, or Kiwanis Club.

The names and addresses of other groups follow. They all help deaf-blind people in one way or another. If you live outside the USA, the international associations may help you. They could tell you about groups in your country.

Ms. Sandra Meyer
Director of Correspondence Education
John Tracy Clinic
806 West Adams Blvd.
Los Angeles, CA 90007
USA

The Tracy Clinic has a course they will send by mail. It is for parents of deaf-blind children. It has lessons to give your child before he starts school. You need to write the Clinic from time to time. They want to know how your child gets along with his lessons. They will answer your questions. The course is free. It will be sent in English or Spanish.

Services to the Deaf-Blind
Hadley School for the Blind
700 Elm Street
Winnetka, IL 60093
USA

Hadley School has a course for young people and adults who read Braille. It is called *Independent Living without Sight and Hearing*. The course is free to a person who is deaf and blind. It tells a person how to do things for himself and get around by himself.

Mr. Martin A. Adler, Director
Helen Keller National Center
for Deaf-Blind Youths and Adults
111 Middle Neck Road
Sands Point, NY 11050
USA

There are eight centers in different parts of the USA. The center will answer questions about deaf-blindness. It assists local groups in serving deaf-blind people near their homes. The center in New York tests and trains deaf-blind people.

National Easter Seal Society
2023 West Ogden Avenue
Chicago, IL 60612
USA

They test and treat people with all kinds of physical problems. They have offices all over the USA. To find the office near you, write the address above.

National Association for the Deaf-Blind
2703 Forest Oak Circle
Norman, OK 73071
USA

This group will advise parents about problems. They also refer to other groups. They may help a local parents' group to get started.

Closer Look
P.O. Box 1492
Washington, DC 20013
USA

This group may be able to answer questions and refer you to people near you who can help. They send a newsletter twice a year.

North American Association for Services
to Deaf-Blind Children and Youth
999 Pelham Parkway
Bronx, NY 10469
USA

This is a group of teachers, parents and others. They can answer questions and refer people who need help.

National Association for Deaf-Blind
and Rubella Handicapped
86 Cleveland Road
Ealing, London W13
England

They have a mother-baby course. They can answer questions and refer people.

International Parents' Organization
for the Deaf
3417 Volta Place, N.W.
Washington, DC 20007
USA

Parents from all over the world belong to this group. They stress speech along with hearing aids for deaf-blind children. They can answer questions about deaf-blindness. They can also refer you to other groups that can help.

International Association for Parents
of the Deaf
814 Thayer Avenue
Silver Spring, MD 20910
USA

Parents from all over the world belong to this group. They stress speech, signing, and fingerspelling along with hearing aids for deaf-blind children. They can answer questions and refer you to other groups that can help. Their newsletter, *The Endeavor*, has a supplement on deaf-blindness.

Dr. Susan Jay Spungin
Director of National Consultants
American Foundation for the Blind
15 West 16th Street
New York, NY 10011
USA

This group has a catalog of vision aids. They may also be able to answer questions about problems you have.

National Library Service for the Blind
and Physically Handicapped
Library of Congress
Washington, DC 20542
USA

The Library has talking books and Braille books for people who are blind. Your local library must send the request for you.

There are many groups that can help with some of your problems. If a group can not help, they may tell where you might get help.

SOME DEAF-BLIND PEOPLE

☐ Mike Price has Usher's syndrome. This is hearing loss from birth and vision loss starting in the teens. Mr. Price puts parts together for an electronics company. He lives near his job and walks to work. He uses speech and says he has to be careful to talk clearly.

☐ Anthony Fuller's deaf-blindness is due to rubella. He attended a residential school for the

blind. He is 22 years old and lives in a house trailer near his parents.

His job is cleaning a high school. His boss is very pleased with his work. Anthony likes to telephone and he uses his hearing aid with the phone. Water skiing is a sport he enjoys.

☐ Eddie Patterson is 16 years old. He was born with a vision loss that got worse and worse. His hearing loss began before he was two years old. Eddie is in a class for the deaf during the day. His speech is not clear so he signs and types notes.

Eddie enjoys TV shows with a lot of action. His family lives in the country and he takes care of cows, dogs, and cats.

☐ Of course, the most famous deaf-blind person was Helen Keller. Her deaf-blindness was caused by an illness when she was a baby. She learned to talk, but her speech was not easy to understand. With the help of her teacher, Anne Sullivan, she went to Radcliffe College.

Helen Keller traveled all over the world to improve the lives of other blind people. During her life she met many of the best known people in her country. She was world famous for the way she overcame her deafness and blindness.

THE FIRST STEP IS THE HARDEST.

—MARIE DE VICHY-CHAMROND

☐ Additional copies of this booklet are available from

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